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Title page: Experiences of low iodine diets in the treatment of differentiated thyroid cancer with radioactive iodine ablation therapy

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Abstract

Background and aims: International guidelines on the treatment of differentiated thyroid cancers (DTC) promote the use of low iodine diets (LID) prior to radioactive iodine remnant ablation (RIA), as high iodine status may interfere with radioiodine uptake. Most UK treatment centres adhere to these guidelines and advise people to consume a LID. There is limited research as to how people cope with the LID or its impact on daily life and wellbeing, and no studies have been conducted in the UK. This study explored peoples' views and experiences in relation to consuming a LID during treatment for DTC with RIA.

Methods: Twenty-eight semi-structured interviews were conducted with people from across three treatment centres where differing advice had been delivered regarding a LID. Interviews were recorded, transcribed verbatim and key themes were developed through inductive thematic analyses.

Results: Individuals advised to consume a LID believed that adhering to the diet would help their treatment. Most restricted their diets beyond what was recommended and there was confusion surrounding what they could eat as part of the diet. Food selection and preparation were important which included substitution of foods and ingredient checking. Being on the diet was considered to have both a physical and psychological impact.

Conclusions: The findings of this study provide a qualitative insight into the lived experiences of people with DTC in relation to consuming a LID. The results have relevance for professionals providing dietary guidance at oncology centres treating patients with RIA therapy in the UK.

Keywords: low iodine diets; differentiated thyroid cancers; radioactive iodine remnant ablation; interviews

Standard abbreviations: DTC = differentiated thyroid cancers; LID = low iodine diets; RIA = radioactive iodine remnant ablation

Introduction

Thyroid cancer is the most common form of endocrine tumour and the incidence rate is increasing (1). DTC accounts for 95% of cases and there is a long-term risk (10-30% of cases (2)) of recurrence with this type of cancer (3). Treatment is usually total thyroidectomy, followed by RIA with ^{131}I to destroy any thyroid tissue left post-surgery (4). To ensure the uptake of ^{131}I, thyroid stimulating hormone (TSH) must be raised and this is either achieved through thyroid hormone withdrawal (THW) or, more commonly, using Thyrogen™ (rhTSH) injections. In addition, high iodine status may impair uptake of RIA and a LID of varying duration, but usually 1 or 2 weeks, prior to RIA may be advised(4-6). In 2016 the UK Low Iodine Diet Working Group developed and distributed a UK LID diet sheet, and this is widely used in practice (7). However, urinary iodine concentration is not routinely measured, and dietary intake is not recorded; so the level of adherence to advice is unclear.

There is limited research as to how people manage the LID or its impact on daily life and wellbeing. Although opinion pieces suggest that people face various challenges on the diet e.g. confusion with advice, feelings of anxiety, excessive restriction (8) no studies have been conducted in the UK. An interview study in Canada (9) investigated overall patient experiences of receiving RIA for thyroid cancer and reported that the LID caused particular concern although limited details on this were provided. Another study in Korea explored people's experiences of the LID during preparation for RIA (10). They found the diet negatively disrupted peoples' lives and it led to feelings of isolation and exhaustion. However, the participants in that study were also experiencing THW so some of the findings could have been attributed to the alteration in medication and not the diet. Furthermore, the study took place in Korea, a country with a very high median iodine intake (>375mcg/d) due to the consumption of seaweed and fish (6); as such, the findings may not be applicable to the UK context where iodine intakes are generally low (median urinary iodine concentration for adults (men and women) aged 19-64yrs = 105mcg/L)(11).

This study aims to explore the views on, experiences of, and adherence to a LID during treatment for DTC with RIA, among people treated at UK centres that offered varying LID advice. This study will aid professionals who are advising LIDs by increasing understanding of the impact of dietary advice on people's lives. It is also important to determine whether there is a substantial patient burden in following a diet for which there is currently little evidence of benefit (12).

Materials and methods

Twenty-eight semi-structured interviews were conducted to explore the dietary experiences of people during treatment for DTC with RIA. Participants were recruited from three centres treating thyroid cancer in the UK which offered different advice: site 1 advises people to follow a LID for 2 weeks prior to RIA, and 48 hours after; site 2 advises people to follow a LID for one week prior to RIA; and site 3 does not advise a LID.

Eligibility criteria included being aged 18 years or over, having received RIA therapy for DTC for remnant ablation or for recurrence and having been prepared with rhTSH. In 2014 the 3rd Edition of guidelines for the management of thyroid cancer in adults was published, and we therefore recruited people who had received RIA from 2015 onwards as they were likely to have received treatment in accordance with these guidelines. Having had treatment more recently also helped individuals to recollect their experiences of a LID. People with anaplastic or medullary thyroid cancer, and who had received RIA for reasons apart from thyroid cancer were excluded. People unable to speak or understand English, who couldn't give informed consent were also excluded. Those prepared with a THW protocol were also excluded, as their priorities, opinions and experiences of the LID may be different to those prepared with rhTSH as the former is associated with greater morbidity. Potential participants were identified and screened for eligibility by clinical staff (e.g. radiographers, nurses) and if they fitted the criteria were given a brief information pack following treatment for RIA. Those expressing a wish to take part contacted the study team and a suitable interview date and time was decided. Participants were asked to answer a short demographic questionnaire before the interview. The interviews were between 15.5-49.5 minutes duration. Interviews continued until data saturation had been reached when no new themes were emerging during the interviews.

Ethical approval was obtained from the East of England - Cambridgeshire and Hertfordshire Research Ethics Committee (18/EE/0313). Consent was obtained for all interviews.

Data analysis

Analysis was carried out with the aid of the NVivo V.12 software package. In keeping with the iterative nature of qualitative research, initial interviews were reviewed and the topic guide was revised accordingly. Interviews were conducted by GH and AS, audio-recorded with participants' written or verbal consent and transcribed verbatim by an approved transcription service. The transcriptions were read and reread for familiarisation with the data and were

analysed within an inductive thematic approach. An open coding exercise was undertaken by GH and AS by repeatedly reading passages of text, sentences and paragraphs. Where there were discrepancies in meaning of text and ascribed codes these were discussed by GH and AS until consensus was achieved. This approach led to the development of a definitive coding framework by which all transcripts were coded. In addition, this approach supported the inductive development of themes and sub-themes emerging within the data. To improve rigour in this process GH, AS and CE met to discuss emergent themes and reach overall consensus prior to presenting the definitive themes below.

Results

Table 1 shows the characteristics of the participants from each study site (site 1: N = 11; site 2: N = 9; site 3: N = 8). Nineteen were female and 9 were male which is representative of the disease, which is approximately three times more common in women (13). Most individuals were White British in full-time employment and had obtained a higher education qualification. The participants' ages ranged from 24 to 80 years old (average age: 51).

Table 1: Participants' profiles (n=28)

Site/ No.	Sex	Age at interview	Ethnic group	Marital status	Employment	Highest education qualification
1/1	Female	57	White/white British	Married	Full-time	O level/GCSE or equivalent in other country
1/2	Male	30	White/White British	-	Full-time	Degree or other higher education
1/3	Female	49	White/White British	Married	Full-time	O level/GCSE or equivalent in other country
1/4	Female	24	White/White British	Single	Part-time	Degree or other higher education
1/5	Male	59	White/White British	Married	Full-time	O Level/GCSE or equivalent in other country
1/6	Male	34	White/White British	Cohabiting	Full-time	Degree or other higher education
1/7	Female	71	White/White British	Married	Retired	Degree or other higher education
1/8	Male	34	White/White British	Single	Full-time	Other qualification - intermediate apprenticeship
1/9	Female	34	White/White British	Married	Part-time	Degree or other higher education
1/10	Female	32	White/White British	Cohabiting	Part-time	Diploma
1/11	Female	48	White/White British	Married	Part-time	A level or equivalent in other country
2/12	Female	46	White/White British	Cohabiting	Full-time	Degree or other higher education
2/13	Female	38	White/White British	Married	Full-time	Degree or other higher education
2/14	Female	59	White/White British	Married	Retired	A level or equivalent in other country
2/15	Female	76	White/White British	Married	Retired	O Level/GCSE or equivalent in other country
2/16	Male	47	White/White British	Married	Self-employed	Degree or other higher education
2/17	Male	49	White/White British	Married	Full-time	Degree or other higher education
2/18	Female	48	Black/African-Caribbean/Black British	Single	Full-time	Degree or other higher education
2/19	Female	28	White/White British	Single	Full-time	O level/GCSE or equivalent in other country
2/20	Male	57	White/White British	Cohabiting	Part-time	Degree or other higher education
3/21	Female	57	Asian/Asian British	-	Full-time/Statutory sick pay	No formal qualifications
3/22	Female	69	Mixed/multiple ethic group Black/African Caribbean/Black	Divorced	Retired/permanently sick or disabled	Degree or other higher education

			British			
3/23	Female	53	White/White British	Separated	Full-time	A Level or equivalent on other country
3/24	Male	54	Irish/White	Married	Full-time	Diploma
3/25	Female	80	White/White British	Married	Retired	Diploma
3/26	Male	64	White/White British	Single	Retired	O level/GCSE or equivalent in other country
3/27	Female	63	White/White British	Widowed	Retired	Degree or other higher education
3/28	Female	60	White/White British	Married	Part-time	Degree or other higher education

Five key themes (theme 1: attitudes and adherence; theme 2: dietary restriction; theme 3: confusion; theme 4: food selection and preparation; theme 5: physical and psychological impact) emerged from data analysis relating to experiences of a LID before RIA treatment.

Theme 1: Attitudes and adherence

All participants from the advice sites were aware of the LID and reported adapting their food intake to follow the diet. Most of these participants recalled that they carried out the LID for the advised timeframes. Half of the participants from the no-advice site were aware of the diet and two of the eight adapted their food intake, consuming a LID for 4 and 6 weeks respectively. Those in the no-advice site who had come across information about the LID from other sources (the internet, friends) but who had not followed the diet didn't report any confusion or distress at discovering this additional information. Many of those who had been given the dietary advice held strong beliefs that if they didn't adhere to the diet their treatment may not be as effective.

> *I found it very simple just to switch over for two weeks, knowing that I had to do it … If I didn't do this then this treatment wouldn't work and I'd be back in for another, following treatment where I'd have to go through the LID again. (1/2: Male, age 30)*

> *It's easily understandable why you have to go on that diet. Without it, the treatment isn't as effective, so I'd rather the treatment be effective and try and get cured than eat stuff that I'm normally eating... (2/20: Male, age 57)*

Some reported accidently eating products that may have contained iodine and used language expressing concern over their actions e.g. 'messed up' and 'damage' and thought it may have negative implications for their treatment.

> *Then when I went in, I explained that I'd messed up, so they had to look into it. I think they went to see Doctor [Name] then to see if it was okay to continue, which it was at that time. (2/20: Male, age 57)*

Individuals felt they understood the rationale for carrying out the diet and most were able to provide detailed accounts of how they thought the LID would help their treatment. Some combined this with visual description or analogies:

> *…when they explain it to you that you're starving your body of something and then when they give it the treatment it's almost like a Pac-man effect, it's like "Yummy, yummy, yummy. Here it comes, let's grab it." (1/3: Female, age 49)*

For a few, the diet offered control over their treatment at a time when they felt disempowered.

> *I wanted to make sure that I was really strict, because at the end of the day, that is something that I can kind of control. As long as I have a low iodine diet, then I have done everything I can to make sure that that treatment works, or hopefully works. You have to wait nine months to find out if it has actually worked. (1/4: Female, age 24)*

Many participants reported finding the LID easy to follow because in the context of cancer they thought they had the 'good cancer' and the easier cancer journey without chemotherapy.

> *I mean compared to having chemotherapy or radiotherapy, anything like that, if this can sort it out and it means me not on anything else, it's far easier on me and my family than anything else… (1/11: Female, age 48)*

They also reported that they were able to adhere to the diet because it was only for a short period of time (1-2 weeks):

> *No, I figured it was only for two weeks, so it's not a long-term thing, bear with it for two weeks, and then I can have what I want. (1/9: Female, age 34)*

> *I think if it had been a month, I probably would have been like, "Oh, it's too much." (2/19: Female, age 28)*

The reported level of ease or difficulty also depended upon the degree to which the diet interrupted their normal dietary rhythm.

> *We found it quite easy. You hear any diet, you think, "This is going to complicated." It wasn't. It wasn't far away from what we were eating, not at all. (1/5: Male, age 59)*

Support from healthcare professionals, family and friends played an important role in ensuring adherence.

… my parents, obviously, were here as well, so they've just reminded me not to have milk and stuff (1/8: Male, age 34)

… it was my friend that helped me. I gave the list to my friend, because I'm a bit dipsy. (Laughter). (1/10: Female, age 32)

Theme 2: Dietary Restriction

All participants that went on the LID described the dietary restriction that they experienced and most reported craving or missing consuming their favourite foods such as chocolate and dairy.

Yes, I think the biggest thing was not eating cheese and milk. I stuck to almond milk, I think it was. I think it was the dairy bit of it that was the most difficult really. (2/14: Female, age 59)

For many, the level of restriction went beyond what was recommended. For example, there were reports of caution or concern having eaten a nugget covered in breadcrumbs, when deciding to eat a piece of birthday cake or tasting a sauce due to the iodine content and the effect this may have on treatment.

I couldn't eat any of it and I couldn't taste it either. I don't know whether you're a cook but just checking that things are right. I had to get my husband to taste the chocolate mousse…(1/7: Female, age 71)

Some individuals reported restricting their diet further than recommended to include no iodine.

…if I can go all low iodine and not have any at all then it would probably bode well for a better response in the treatment. I really stuck to it, I didn't even have the allowed guidance which you could potentially have. (1/2: Male, age 30)

It is noteworthy that a couple of participants reported continuing with the diet and restricting their iodine content longer than recommended by healthcare professionals. One individual reported restricting their iodine intake for up to a year in fear that not going so may result in reoccurrence of the cancer.

I'm probably still sometimes a bit nervous of them…I think because thyroid cancer has such a high probability of recurring that I'm always aware, I always somehow think I could be giving a little bit of fuel to some remnant cells somewhere, make it go on the rampage, which is, again, possibly neurotic, but it's just in the back of my

mind…I would say, yes, certainly for a year afterwards, I didn't eat fish and I was quite neurotic about iodine. (2/12: Female, age 46)

Past and current dietary restriction was found to either help or hinder consuming a LID. Some felt it was an easy diet to follow because they had previously restricted their diet for other health, lifestyle and /or ethical reasons and as such further restriction was viewed as not being too onerous:

I think it was just easier because we had already gone through that change where we were trying to change our diet as it was. Another change, in January, wouldn't seem to be too much for two weeks. It was a bit like, "Oh well, it's just another thing that I need to do at that stage." (1/2: Male, age 30)

Others expressed that their diet was already restricted so the LID diet was challenging adding further restriction to the foods they could consume.

I am vegetarian so I did find the diet very hard. (1/4: Female age 24)

An individual who had experienced recurring thyroid cancer and had therefore been on the diet several times, reported particular restriction during the last treatment cycle.

I think each time, probably the last time I've been even more obsessed kind of thing. My husband was saying, "Surely one cup of tea a day would be fine in the mornings with normal milk." Possibly the first or second time I may have had the odd cup of milk and stuff like that. This time I made sure I didn't. Sometimes you may eat something that you think, "Oh my gosh, that might have had dairy in or iodine." Literally once I find something that hasn't got any iodine or low iodine in, this time I was living on a jacket potato. (1/3: Female, age 49)

Theme 3: Confusion

This theme describes the confusion individuals experienced whilst being on the LID. The most common was confusion surrounding what they could eat as part of the diet which caused additional concern and stress. There was particular concern regarding salt and whether items contained iodised salt but also salt in general.

I did quite a bit of research online, because I found it quite confusing, really, about what you can and cannot eat – particularly the salt bit, so in the end I just… My husband kept saying, "You can't eat that. You can't eat that." In the end, I just didn't eat any salt, really. I tried to cut it all out. I wasn't quite sure which I was meant to have or not. (1/1: Female, age 57)

….the things I found difficult were where it was the iodine in the salt, trying to get the clarification of whether it was sea salt, or UK sea salt in things. (2/17: Male, age 49)

Although the internet was a useful resource for some, especially those from the no-advice site, a dominance of American medical literature online extended the confusion.

…because they did say, "Oh, don't read too much online about the LID, because you'll find a lot of American information," and I think their [salt] is iodised, isn't it, and ours isn't. So, yes, I found that a little bit confusing (2/19: Female, age 28)

A few participants reported that the confusion had caused them to limit their food intake and skip meals or repeatedly eat the same meal they considered to be low in iodine.

I did get a bit confused about the whole thing, so I just really limited my diet to a few recipes and I just repeated them over and over again. At the end of it, I was, kind of, getting a bit desperate for food. (1/1: Female, age 57)

For some, eating a LID in the hospital was a challenge and confusing due to non-low iodine options being offered or products that they thought they couldn't eat:

I had to keep reminding them. Even though it said on my door, 'low iodine diet,' they kept bringing me the wrong menu. So one time, they were trying to give me tagliatelle with a cream sauce on it. The other thing was corned beef hash. I was trying to explain that was made with mashed potato, and they put milk and butter in. (1/10: Female, age 32)

Healthcare professionals were a trusted source of information and helped settle confusion. Repetition of the diet was also considered to ease confusion.

I think it was quite easy this time because I'd done it twice before, so I'd got a bit of an old hand at it, but I think the first time it was more difficult because just I got quite confused about what I could have. (1/1: Female, age 57)

Theme 4: Food selection and preparation

Whilst on the LID, people reported being careful before buying and consuming foods, checking products for their iodine content.

> *Then they were saying about seaweed. I wasn't sure what that might be in in terms of food…So being very careful what you buy as well. (3/24: Male, age 54)*

The main resource to help people in their decision-making in whether to consume an item of food was the UK Low Iodine Diet Working Group's diet sheet. Everyone from the advice-sites referred to this source and it was considered an informative and useful resource. It laid out which foods were high in iodine that should be avoided and those which were low in iodine that could be consumed. For some, the UK LID Working Group's diet sheet provided security that they were consuming the correct foods.

> *Also, it got me checking the labels on the ingredients a little bit more thoroughly just so I could prep a couple of days before going on the diet and then also during the diet, I'd look and see, "This is okay or not." (1/6: Male, age 34)*

> *I used to keep that [referring to the 'diet sheet'] in my bag, so when I went shopping, I could look at the list and then look at what was in it, and see whether or not- Because I kept forgetting. (1/10: Female, age 32)*

There were accounts of people emailing food companies and examining ingredient lists of products to find out the levels of iodine to check if they could eat them. Some participants discussed the extra time it took at the supermarket to check if products had iodine in and the difficulty of reading ingredient lists:

> *Just going to the supermarket, taking so long to check products that haven't got iodine in, that's the only hard part is identifying the products you can't have. (1/5: Male, age 59)*

> *But it's very difficult to find, although everybody says to you, "Everything has to be labelled with everything so you should see what it's..." but actually finding iodine in a list of ingredients isn't possible. It's not listed as iodine. You can't actually do that. (1/7: Female, age 71)*

Many participants spoke about substituting products that were high in iodine with those that were low. Substitutions for milk were discussed by most people particularly because of its importance in tea, coffee and cereal. Participants reported trying non-dairy substitutes for milk such as soya, oat, rice and coconut. There wasn't a consensus on

preference for a milk product substitute as palatability varied between participants. Other substitutions included swapping milk for dark chocolate, butter for dairy-free spreads and consuming gluten free products. One individual reported switching to a vegan diet.

> *…but I did, basically, a vegan diet. That worked out well, because it had no milk and no egg in it…(1/10: Female, age 32)*

Forward planning and preparation of low iodine food/meals e.g. bread facilitated the consumption of a LID. A couple of participants reported that they found the diet sheet on the internet prior to their appointment with a HCP which had helped them to prepare for the diet.

> *Definitely having that list a couple of weeks before was really handy just so I can think in my head, "Next week I won't be able to eat this. I won't be able to eat this." Also, it got me checking the labels on the ingredients a little bit more thoroughly just so I could prep a couple of days before going on the diet and then also during the diet, I'd look and see, "This is okay or not." (1/6: Male, age 34)*

Most participants discussed the support they had experienced from family and friends in the form of reminding, cooking and checking to adhere to the diet. For some there was a reliance on others; for example, one participant spoke about their experience of eating high iodine food during the diet phase and attributed this to his wife forgetting:

> *Well, yes, and that's who messed up, really, because she [referring to their wife] completely forgot and then had done the fish. I completely forgot as well. (2/20: Male, age 57)*

Eating in and out of the home was difficult for some due to the limited food they felt they could eat:

> *I didn't go out. I wouldn't have went out, I didn't. I didn't think it was worth the risk because you never know what's in it. (1/5: Male, age 59)*

A few participants discussed repeatedly eating the same meal due to a lack of time to prepare and organise a LID meal:

> *I was back at work, so I just used to have jam sandwiches, usually. (Laughter) (1/1: Female, age 57)*

Theme 5: Physical and psychological impact

Finally, this theme describes the impact of the LID on peoples' body and mood. Many reported finding the diet easy and some stated that it helped them to lose weight and feel healthier. A couple of individuals however spoke about how emotionally vulnerable they were feeling after their cancer treatment and experienced the diet as an added difficulty and burden:

> *Yes, it is not long, you know that there is a light at the end of the tunnel. You know that you can go and eat whatever you want afterwards. But when you are already experiencing… Your emotions are all over the place because you have just been told you have got cancer. You have just had surgery or whatever and now you have got to take more treatment that you don't know is definitely going to work and then you have got to go and do this [referring to the LID], it is a lot. (1/4: Female, age 24)*

Early feelings towards the LID were challenging for some with initial apprehension or a negative mood:

> *You know, a little bit grumpy at the start, because I was finding my feet with, you know, what I could and couldn't eat. (1/8: Male, age 34)*

> *It wasn't that difficult because, I mean, after the initial… I wouldn't say cold turkey but a day or two of 'grrr' I was kind of over it and just focused on it and just got on with it. (3/24: Male, age 54)*

A few participants voiced the fatigue they felt from being on the diet while others found the diet boring and struggled with the monotony of repeatedly eating the same foods. A few discussed the moment when the recommended time to be on the diet had elapsed. There was a feeling that participants were 'watching the clock' and there were reports of euphoria and relief when they could return to their normal diet and "over indulged" (1/3: Female, age 49) in the food that they had restricted. One of the sites recommends that people continue the LID for 48 hours after discharge. One person voiced their "disappointment" (1/8: Male, age 34) of having to continue the diet when they came out of hospital.

Discussion

The aim of the present qualitative study was to explore the views and experiences of people in relation to being advised to consume a LID during treatment for DTC with RIA. Semi-structured interviews were conducted with people from across three treatment centres where differing advice had been delivered regarding a LID.

Any dietary change can be difficult to make and to sustain but individuals in this study reported high compliance with the LID. Other studies exploring people's experiences of the LID have also found that people took an active role in following the diet (10). The ease of behaviour change could be due to participants considering their type of cancer to have an easier treatment journey compared to others involving chemotherapy. The 'good cancer' label assigned to thyroid cancer is often considered negatively (14) but in this study it was possibly one of the antecedents that drove behaviour change. Another reason for the adherence to the diet could be that there was clear coherence such that individuals could understand the putative mechanism of therapeutic action through a process of visualisation. Guided imagery (visualisation) uses the power of the imagination to help an individual relieve symptoms caused by cancer or cancer treatment. Many people find that they feel better after they imagine feeling stronger. Some people like to visualise their body fighting off the cancer cells (15). Participants in this study were able to visualise how depleting their body of iodine (through the diet) would help the cancer cells to absorb the radioactive iodine. This could have invoked individuals' sense of control and empowerment in their recovery rather than being a passive recipient of care.

This study found individuals receiving advice at a hospital setting were generally knowledgeable about the timeframe of the diet. However, a couple of individuals from the hospital site that did not deliver LID advice reported adhering to a LID and for a greater timeframe than recommended. People have been reported to misunderstand LID timeframes in the past (16), and this study suggests that this may be particularly an issue for those not receiving dietary advice from a hospital. Centres that do not offer formal advice may want to acknowledge that their patients are likely to encounter LID advice elsewhere, reassure them that evidence for any benefit to standard treatment is weak and there is no evidence of benefit from restricting dietary iodine for more than two weeks.

Restriction was a strong theme discussed by most participants in the present study. This restriction went further than recommended both in terms of time and dietary choices probably due to a strong belief that the diet was going to influence treatment. Part of this restriction is due to the confusion about what could be consumed on the LID. Previous studies have found that peoples' knowledge on acceptable foods on this diet is limited (9, 16). In line with previous accounts in relation to the LID (8, 16) there was particular confusion surrounding salt. Moon et al (16) found the majority (88%) of people in their study believed that a LID was a low salt diet, despite the fact that refined salt is not iodised in Korea. Salt is iodised in some countries such as North America as a way of combating iodine deficiency disorders. This is not necessary in the UK because, historically, it was thought that the populations' diet is generally

sufficient in iodine (17). Despite individuals being advised that there was international disparity, the prominence of American literature on the internet potentially exacerbated confusion especially in relation to salt and manufactured foods containing salt. This confusion partly led to people limiting their food intake, skipping meals or repeatedly eating the same meals. This is in accordance with previous research which has shown that people substantially reduce their food intake during the LID (a reduction from 1771 (SD 514) kcal/day to 1325 (349) kcal/day, $p<0.001$) which was partway attributed to a lack of knowledge of which foods are high or low in iodine (6).

People reported both perceived benefits of going on the diet e.g. weight loss and perceived challenges e.g. fatigue and boredom. Behavioural strategies to adhere to the diet included substituting products (e.g. cow's milk for soya) and checking products for their iodine content by examining their ingredients list, discussing with healthcare professionals or contacting companies. Preparing low-iodine meals is a previously cited perceived barrier in relation to consuming a LID (16), and indeed this study supports this finding as planning and preparation were reported as facilitating factors to its consumption. Social support from family and friends who would cook, remind or check ingredients also facilitated adherence. The findings of this study suggest that there were implications for significant others and family members who may have been involved in food shopping and preparation such that a LID and the pressures to adhere to the diet were also imposed on them.

The present study found that individuals held a strong belief in the diet and were self-blaming and anxious if they had consumed food containing iodine, and so logically there is concern that people may partly attribute treatment failure to their actions during the LID phase. Previous research supports this notion as participants have been reported to be apprehensive that failure to follow the diet correctly might have affected treatment outcomes (9). There is also another opportunity for guilt and blame if the person relapses. The LID may add to the psychological distress of thyroid cancer recurrence (18, 19) which is a concern if there is little evidence of benefit (12).

Although this study suggests high adherence to the diet, it is possible that those coming forward for interview had a particular interest in their health and wellbeing, relished having authority over their diet, and an active role in their treatment and could be considered as information seekers.

The present qualitative findings have implications for clinical guidance at oncology centres treating patients with RIA therapy in the UK. Healthcare professionals should consider the level of ease that patients can adapt their diet and

whether it caused an interruption to normal dietary rhythm. Even if patients are not being given advice to follow the diet in a hospital setting, healthcare professionals should be aware that people maybe following it based on their own research. Alongside the provision of the UK diet sheet which offers solutions to the nutritional misunderstandings and confusion in relation to the diet, it may be useful for professionals offering this dietary advice to patients to be aware of the behavioural and nutritional issues that can arise (Box 1).

Box 1: Behavioural and nutritional issues that can arise from going on a LID and associated advice based on the Low Iodine Diet Working Group recommendations

Issue - either participant reported(*) or researcher identified	**Advice (20)**
Salt*(21)	• Salt in the UK is not routinely iodised. • Emphasise that sea salt from UK manufacturers is not high in iodine (typically 1ug iodine/gram salt). • Iodised salt is not sold in many shops, although some shops selling mainly non-UK brands may sell imported iodised salt including imported Himalayan pink salt. • UK food manufacturers do not usually use iodised salt or iodised sea salt in products.
Specific foods substitute list*	Dairy • Suggest oat, nut, rice or soya milk and yogurt to replace cow, goat or sheep milk and yogurt. • Some brands of non-dairy milks, yogurts, cheeses and ice creams are fortified with iodine, or contain carrageenan (E407, E407a), patients should be reminded to check the label. • Sweetened non-dairy chocolate (typically sold in 'free from' sections or health food shops) or dark chocolate to replace milk chocolate.

	Egg • Iodine in egg is concentrated in the yolk. One egg yolk contains approximated 25mcg iodine and one egg white approximately 2mcg iodine. • Common retail mayonnaises are mainly vegetable oil and contain approximately 7mcg iodine/100g. • Many biscuits and cakes are not made with milk, butter or whole egg and contain only trace amounts of iodine. Remind patients that they do not need to exclude all cakes and biscuits but to check ingredient lists. Bread and coated foods • Most bread sold in the UK is low in iodine. • Soda bread (made with milk), ciabatta and French baguettes may be higher in iodine. • Coated non-fish/seafood items (e.g. coated or battered chicken / battered sausage) are low in iodine.
Switching to a vegan diet Knowing what to eat on a vegetarian diet	Remind patients that not all vegan foods are low in iodine. • Agar-agar and other seaweeds may be used in place of gelatine. Alternate non-dairy protein sources • Beans and pulses (e.g. lentils, chickpeas, kidney beans). • 30g nuts/day. • Tofu coagulated with calcium carbonate, texturized vegetable protein, seitan, quorn. • Vegetarian sausages, burgers, falafel (although check the ingredients list).

Level of restriction	If struggling on the diet, remind patients that it is a low iodine, not a no iodine diet.
Length of diet	Professionals should be aware of stressing the timeframe of the diet and that it is unnecessary to continue beyond this. Be aware that some patients may falsely believe that iodine 'feeds' thyroid cancer and that long-term restriction will prevent recurrence.
Sources of iodine on ingredient lists	Milk Milk powder Whole egg Dried whole egg Egg yolk Nigari (bittern) – may be used to coagulate tofu and is a source of iodine. Seaweeds (and derivatives) • Carrageenan (E407, E407a) • Agar-agar • Kombu • Wakami • Kelp • Nori • Sea lettuce/sea spaghetti/sea greens/sea kale • Laverbread

371

372 **Conclusion**

373 The findings of this study provide a unique qualitative insight into the lived experiences of people with DTC in the UK in
374 relation to consuming a LID. Although only advised as a short-term dietary intervention, this study has shown that while
375 most people were willing and able to make the suggested dietary changes, making them is disruptive and for a few, the

LID can have a prolonged impact on diets and lives. It is therefore important to reach a consensus within the UK on the overall necessity to use a LID and its duration.

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Statement of Authorship

All authors contributed to the design of the study. GH and AS conducted the interviews. GH, AS and CE conducted the analysis and wrote up the study. All authors read and commented on the final manuscript.

Conflict of Interest Statement

IHS is the lead and LM is a member of the UK Low Iodine Diet Working Group.

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